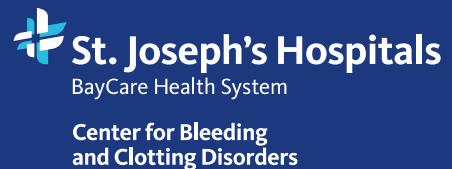


Updates from your HTC

News for Patients, Families and the Community.



Our Team

Medical Director:
Erin Cockrell, DO

Pediatric Hemophilia
Nurse Coordinator:
Lisette Sanchez, RN

Adult Hemophilia and
Pediatric Thrombophilia
Nurse Coordinator:
Recruiting

Social Worker:
Adrienne Abecassis, MSW

Clinical Pharmacist:
Lena Charafi, PharmD

Research Coordinator:
Lindsay Dembinsky, RN

Data Coordinator:
Diane Telegdi, RN

Physical Therapist:
Tracey Dause

Contact Us

3001 West Dr. Martin
Luther King Jr. Blvd
Tampa FL 33607
813-554-8294



St. Joseph's HTC: What's New?

Dear patients, it is with great sadness that we announce SueEllen's departure from our HTC. We are very grateful for the outstanding care she provided to our patients. We hope that you will join us in wishing her all the best in her upcoming endeavors...

Letter from SueEllen Kremper, RN

It is with a heavy heart that I announce that I will be leaving the Hemophilia Treatment Center. It was not an easy decision to make, but I have accepted another position in BayCare. I feel very fortunate to have had the opportunity to meet each of you and take part in your care. I leave knowing that you will all be very well cared for by the incredible, caring, and compassionate team here at our center.



Hemophilia Treatment Center (HTC) Pharmacy

When you use the HTC pharmacy, you are supporting YOUR HTC and the services we provide for our hemophilia patients. In turn, you receive savings, exceptional customer service, and dependable healthcare.

BayCare HomeCare has provided quality care to patients of all ages since 1976. It is the second largest home care provider in the State of Florida and offers services in 13 counties on the west coast of Florida. The pharmacy, located in Largo, provides infusion and specialty medication to adult and pediatric patients. The infusion and specialty pharmacists are experts in intravenous therapy, which includes IV antibiotics, total parenteral nutrition, inotropes, hydration, factor, and IVIG. They have decades of experience in kinetic dosing, TPN dosing, and management of acute and chronic disease states requiring intravenous therapy. In addition to those services, BayCare Home Care Pharmacy works closely with St. Joseph's Hospital Center for Bleeding and Clotting Disorders to provide continuous care for our hemophilia population.



Melanie Solone is a new hemophilia pharmacist at BayCare HomeCare. She received her Doctor of Pharmacy from the University of Florida in 2011 and went on to complete her Pharmacy Practice Residency at St. Anthony's Hospital in St. Petersburg. After her postgraduate training, she stayed at St. Anthony's Hospital as a Clinical Pharmacist for two years. She became the Oncology Preceptor in the hospital's PGY-1 Pharmacy Residency Program and attained her Board Certification as a Pharmacotherapy Specialist. Melanie continues to use her expertise in drug therapy and disease management at BayCare HomeCare, and closely works with the HTC to provide our hemophilia patients with continuous care.

New Products

The treatment options for hemophilia have advanced markedly in the past decades. These new therapies promise to improve efficacy and the overall patient's quality of life. This year, two new products were approved by the U.S. Food and Drug Administration (FDA) for patients with hemophilia.

Hemlibra (emicizumab)

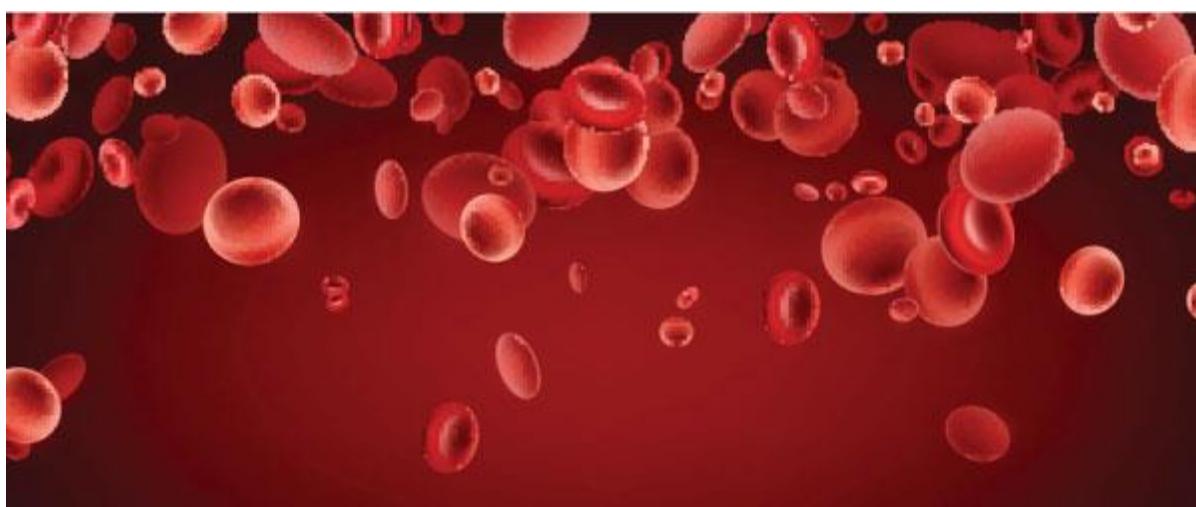
On October 4th, 2018 Genentech announced that the FDA has approved Hemlibra® for **routine prophylaxis** in adults and children, ages newborn and older, with hemophilia A without factor VIII inhibitors. The therapy was already FDA approved in the fall of 2017 for routine prophylaxis in adults and children with hemophilia A with FVIII inhibitors.

Hemlibra® is a therapeutic antibody that works by performing a key function in the clotting cascade that is normally carried out by the FVIII protein. Hemlibra acts like a bridge, bringing activated factor IX and factor X together. This enables the clotting process to continue without needing to replace factor VIII. Hemlibra® is also unique in its administration as the therapy is delivered subcutaneously through an injection just under the skin. Hemlibra can reduce bleeding rates, and it can be administered once weekly, every two weeks or every four weeks.

Jivi

On August 30th, 2018 Bayer announced that FDA has approved Jivi® (BAY94-9027) for the routine prophylactic treatment of hemophilia A in previously treated adults and adolescents 12 years of age or older. The FDA also approved Jivi for on-demand treatment and the perioperative management of bleeding in the same population.

Jivi is a recombinant factor VIII replacement therapy, meaning it replaces the reduced or missing FVIII (a protein needed to form blood clots) in hemophilia A patients. Through its site- specific PEGylation, Jivi has a half-life of 17.9 hours that delivers sustained levels in the blood.



What is RICE?

A general treatment for bleeds and other painful injuries is R.I.C.E.—Rest, Ice, Compress, Elevate

REST

- Stop using the injured area; continued activity may cause further injury, more discomfort, and possible bleeding into tissues or joint
- Rest the injured area for 24 to 48 hours
- Resume activity gradually to prevent hurting or re-injuring the area
- Use a supportive device such as a sling, if needed, to rest an upper extremity; a cane or crutches can help avoid putting weight on an affected leg or foot

ICE

- Use ice to reduce pain and help to constrict blood vessels and limit bleeding
- Apply ice to the affected area for 20 minutes at a time for 48 to 72 hours
- Don't place ice directly on the skin; put the ice in a plastic bag and wrap it in a towel or cloth

COMPRESS

- Wrap the affected area with an elastic bandage to help reduce swelling and limit bleeding; the bandage should be snug but should not cut off circulation

ELEVATE

- Keep the injury extremity (the leg or arm) elevated as much as possible; this helps reduce swelling
- Depending on the bleed site, you may have to limit your activities for a few days following a bleeding episode



Recent Events

Our HTC held its second Health and Wellness event on October 25th which focused on introducing Tai Chi to all of our patients. Why Tai Chi? Research has shown that it can be beneficial for improving balance, flexibility and building strength. But most importantly it is also effective for the treatment of depression and anxiety, and can reduce symptoms of chronic pain by helping to create a sense of inner peace and calmness.

Our presentation was led by our HTC physical therapists, Tracey and Cassie, who did an excellent job sharing information on how to live an active lifestyle. Did you know that for every pound of weight lost, you decrease 4 pounds of force on your knees with every step?

We provided some great prizes to those who participated, which were generously sponsored by both the Tampa Bay Outfitters and the FL Hemophilia Association.

We were also able to present a very well-known member of the bleeding disorders community, named Rick Starks. He shared with us his personal journey and did an outstanding job demonstrating Tai Chi. Rick currently lives in Nebraska and attended the 70th Annual National Hemophilia Foundation (NHF) conference this year; however, he also holds online Tai Chi sessions and is a Reiki Master as well. You can find out more information about him on his website at <https://rickstarks.com/>. Check his Events section for details on future presentations.

Overall, we had a wonderful turnout, and provided additional information on how to get involved with Tai Chi in your local community. If you are interested in these resources, please reach out to your HTC Social Worker Adrienne Abecassis at (813) 870-4017.



Upcoming Community Events

- **National Hemophilia Foundation**

<https://www.hemophilia.org>

- **2019 United Airlines NYC Half Marathon**

- Sunday, March 17, 2019
 - Contact Dilber Karamanci at dkaramanci@hemophilia.org or call 212.328.3731 for more information

- **Washington Days**

- Advocacy opportunity
 - March 27-29, 2019 on Capitol Hill in Washington, DC
 - Contact Conference and Travel Services Manager Alla Vaynshteyn at avaynshteyn@hemophilia.org for more information

- **National Youth Leadership Institute (NYLI)**

- Leadership opportunity for youth ages 18-24
 - Contact Education Specialist Marlee Whetten at mwhetten@hemophilia.org or call 212.328.3735

- **Hemophilia Foundation of Michigan**

- **2018 National Conference- Being Visible: Women with Hemophilia**

- November 9-11, 2018 in Amway Grand Hotel of Grand Rapids, Michigan
 - Contact Patrice Thomas at pthomas@hfmich.org or call 734-544-0015

- **Hemophilia Foundation of Greater Florida**

<http://www.hemophiliaflorida.org/>

- **Product Update Luncheon**

- Sunday, November 11, 2018 at 10am at Brio's Tuscan Grille in International Plaza Mall
 - Address: 2223 North Westshore Boulevard, Tampa, FL 33607



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

1948 - 2018

Created and Hosted By



- Includes exclusive tickets to **Tampa Bay Bucs vs. Washington Redskins**
- RSVP by November 8, 2018
- 1-800-293-6527 or info@hemophiliaflorida.org
- **18th Annual Evening on Broadway**
 - Wednesday, February 6, 2019 at Dr. Phillips Performing Arts Center
 - Address: 445 S. Magnolia Ave, Orlando, FL 32801
 - Orchestra seat tickets are \$390, which includes reception, auction and raffle
 - 1-800-293-6527 or info@hemophiliaflorida.org
- **2019 HFGF Tampa Walk**
 - Sunday April 7th at Al Lopez Park
 - Details to be announced...

- ***Florida Hemophilia Association***

<http://floridahemophilia.org/>



FLORIDA HEMOPHILIA ASSOCIATION

for all bleeding disorders

- **Girls Weekend Getaway**
 - From Friday, November 30, 2018 at 6pm- Saturday, December 1, 2018 at 3pm in the Waterstone Resort and Marina
 - Address: 999 E. Camino Real, Boca Raton FL 33432
 - RSVP by October 26th at admin@floridahemophilia.org/ 305-235-2717
- **2018 End of Year Educational Event**
 - Sunday, December 16, 2018 at 11am in Ty Park Shelter #12
 - Address: 300 N. Park Rd., Hollywood, FL 33021
 - RSVP by December 10th

- ***Camp Boggy Creek*** <http://www.boggycreek.org/>

- **Spring Family Retreat Weekend, Summer Session, and Fall Family Retreat Weekend**
 - Dates to be announced
 - Spring Family Retreat applications will be available November 15, 2018



- Summer Camp application will be available January 1, 2019
 - Parent(s) need to fill out the online application first, then contact HTC Social Worker Adrienne 813-870-4017 who will help to submit Medical Summary
- **Faces of Courage** <http://www.facesofcourage.org/>
 - Santa's Workshop Weekend
 - November 30- December 2, 2018
 - RSVP by contacting Peggie at psherry@facesofcourage.org or call 813-948-7478



- **Children's Cancer Center**

<http://childrenscancercenter.org/>

- This unique organization opens their arms to all of our patients and families with bleeding disorders, including Hemophilia, vWD and Sickle Cell Disease
- Each weekend they hold special events
- Please contact your HTC SW Adrienne 813-870-4017 for a list of specific events and to complete new patient consent form



FYI

For our next event, we are creating an opportunity for you to join us for dinner here in the Medical Arts Building of St. Joseph's Hospital, while we screen the most awe-inspiring documentary called *Bombadier Blood* that just aired for the first time at NHF in Orlando. Please stay tuned for more information...

<https://www.bombardierblood.com/>



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We hope you enjoyed our newsletter and found  
the information we provided helpful.

We welcome any feedback!